

Maine Newborn Hearing Screening Program

Report of Findings

Parent Feedback Survey

August 2008

Prepared for:

The Maine Newborn Hearing Screening Program
Children with Special Health Needs/Genetics
Maine Centers for Disease Control

Prepared by:

Amy N. Black, Ph.D.
Research Associate
Maine Center for Public Health
One Weston Court, Suite 109
Augusta, ME 04330
207-629-9272
207-629-9277 (fax)
www.mcph.org

Table of Contents

Table of Contents	2
Introduction	4
Background	4
Methodology	4
Results	6
Knowledge of Initial Hearing Screening	6
Hearing Screening Refusal	6
Hearing Test Results	7
Feedback on and Satisfaction with Baby's Screening	8
Screening Next Steps	10
Results: Hearing Re-Testing	11
Overall Satisfaction with Re-Testing	11
Results by Code	13
Hearing Results by Code	14
Satisfaction with Screening Services	15
Resources and Additional Screening Program Feedback	16
Babies with Hearing Loss: Early Intervention Services	17
Attitudes about Newborn Hearing Screening	19
Results: Not Screened	21
Explanations for Refusal	22
Attitudes about Newborn Hearing Screening	22
Attitudes about Newborn Hearing Screening	23
Qualitative Results	24
Comments Related to Satisfaction with Screening Services	24
Suggestions for Improving Newborn Hearing Screening Process	25
Survey Feedback	30
Conclusions and Recommendations	31

List of Tables

Table 1. <i>Demographics, total sample (N = 1316)</i>	5
Table 2. <i>Frequencies of when participants first learned of screening</i>	6
Table 3. <i>Frequencies, Hearing Screening Refusal</i>	6
Table 4. <i>Hearing Test Results, Coded</i>	7
Table 5. <i>Respondents' Reported Hearing Test Results</i>	7
Table 6. <i>Respondents' Feedback on Hearing Screening Services</i>	8
Table 7. <i>Respondents' Satisfaction with Hearing Screening Services</i>	9
Table 8. <i>Percent of Respondents Noting Screening Follow-up</i>	10
Table 9. <i>Respondents' Perception of Hearing Re-Test Results, (n = 68)</i>	11
Table 10. <i>Respondents' Satisfaction with Re-Testing, (n = 64)</i>	11
Table 11. <i>Respondent Demographics by Code</i>	13
Table 12. <i>Hearing Test Results by Code</i>	14
Table 13. <i>Respondents' Satisfaction with Hearing Screening Services, by Code</i>	15
Table 14. <i>Educational Information Received</i>	16
Table 15. <i>Early Intervention Services, Babies with Hearing Loss, (n = 8)</i>	17

Table 16. <i>Type of Early Intervention Services Received</i>	18
Table 17. <i>Attitudes toward Hearing Screening, by Code</i>	19
Table 18. <i>Not Screened: Demographics by Refusal</i>	21
Table 19. <i>Knowledge of Hearing Screening, by Refusal</i>	22
Table 20. <i>Attitudes toward Newborn Hearing Screening, by Refusal</i>	23

List of Figures

Figure 1. <i>Average Respondents' Rating on Hearing Screening Services</i>	8
Figure 2. <i>Respondents' Satisfaction with Hearing Screening Services</i>	9
Figure 3. <i>Percent of Respondents Noting Screening Follow-up</i>	10
Figure 4. <i>Respondents' Satisfaction with Re-Testing.</i>	12
Figure 5. <i>Satisfaction with Services Provided by Audiologist, (n= 6)</i>	17
Figure 6. <i>Attitudes toward Hearing Screening, Total Sample</i>	20
Figure 7. <i>Percentage of Respondents Who Would Have Another Baby Screened</i>	20

Introduction

Background

The Maine CDC contracted with the Maine Center for Public Health (MCPH) to help evaluate the Maine Newborn Hearing Screening Program (MNHP). Based on data from the MNHP data system ChildLINK, 97.5% of babies born during the last six months of 2007 ($N = 6970$) were screened ($n = 6794$). Of those, 97.5% ($n = 6622$) passed, with 2.5% ($n = 172$) referred for further testing. Finally, of those who referred only 14 reported some degree of hearing loss (0.2% of those babies screened).

In an effort to explore parents' feedback on and perception of newborn hearing screening, the MNHP created and conducted a survey of parents of newborns born during the last six months (July – December) in 2007. This report summarizes the major findings of the survey.

Methodology

Survey description. The survey was a 30-item questionnaire developed in partnership with MNHP staff as well as a review of others state's parent surveys (i.e., Massachusetts, Wisconsin). The survey was designed to measure feedback from all parents, regardless of hearing test results. Thus, using skip logic, only parents who had babies who were referred were asked to answer specific questions regarding their referral and/or hearing loss.

Survey items included a demographic questionnaire, items regarding parents' knowledge of newborn hearing screening and their baby's results, and their level of satisfaction with the screening process. The questionnaire also included items specifically for those parents with babies who referred and for those who were diagnosed with hearing loss. These items included feedback on hearing screening referrals, results of and satisfaction with referral process. Finally, if their baby was diagnosed with hearing loss, parents were asked to provide information regarding any early intervention services they may be receiving. A copy of the survey is included in the Appendix.

Sampling and Response Rate. Sample participants were obtained through the data system for the Maine Newborn Hearing Program ChildLINK. ChildLINK tracks all infants born in Maine, approximately 14,000 each year, with 6,970 being born between July and December of 2007. Based on this data, surveys were mailed to 6750 parents with current contact information. Approximately 627 surveys were returned for incorrect address making a total sample of 6,123. A total of 1316 respondents returned a survey for response rate of 21%.

Sample Demographics. The majority of respondents were the mother of the baby, Caucasian, and had at least some college or vocational school, with over half holding a college degree. The sample included residents from all 16 counties in Maine. Finally, at the time of the survey the infants ranged in age from 6 – 19 months with the average age being 9.9 months. The demographics of the final sample are included in Table 1.

Table 1. *Demographics, total sample (N = 1316)*

Demographic	Frequency	Percentage
Relationship to Child (<i>n</i> = 1310)		
Mother	1276	97%
Father	34	3.0%
Race/ethnicity (<i>n</i> = 1294)		
Caucasian	1187	92%
African-American	6	0.5%
Hispanic	11	0.9%
Asian-American	16	1.2%
Native American	17	1.3%
Other	57	4.4%
<i>Biracial</i>	50	4.0%
Education (<i>n</i> = 1310)		
Less than some high school	1	0.1%
Some high school	57	4.4%
High School Grad	230	17.6%
Some college or vocational	297	22.7%
College degree	534	40.6%
Graduate degree	191	14.5%
County (<i>n</i> = 1,094)		
Androscoggin	94	8.6%
Aroostook	52	4.8%
Cumberland	267	24.4%
Franklin	25	2.3%
Hancock	45	4.1%
Kennebec	95	8.7%
Knox	26	2.4%
Lincoln	31	2.8%
Oxford	45	4.1%
Penobscot	134	12.2%
Piscataquis	9	0.8%
Sagadahoc	31	2.8%
Somerset	27	2.5%
Waldo	40	3.7%
Washington	33	3.0%
York	137	12.5%
Out of Maine	3	0.3%

Results

Data analysis was conducted using the statistical software, SPSS. Data was first reviewed and cleaned for inconsistencies. Data analysis included frequencies and descriptive statistics of survey questions, as well as tests for statistical significance where applicable. The following section includes a summary of the results for the total sample organized by survey topic.

Knowledge of Initial Hearing Screening

Participants were asked how they first learned that their baby's hearing would be screened. Over 90% indicated that they learned either before they were admitted to the hospital or while they were in the hospital.

Table 2. *Frequencies of when participants first learned of screening*

	Frequency	Percentage
<i>Before admission</i>	532	40.5%
<i>While in hospital</i>	677	51.4%
After hospital discharge	10	0.8%
Not sure	49	3.7%
Other	44	3.3%

Of those respondents who noted "other," most either learned of the hearing screening before the birth of their child or noted that they had never been told.

Hearing Screening Refusal

A small percentage (1%) of respondents refused the hearing screening. Details on this group of respondents, including reason behind refusal, are located in a subsequent section.

Respondents' "Other" Explanations:

Before birth/admission (n = 20)

- Birthing class (5)
- Previous birth (6)
- From a Midwife (5)
- At a Drs appointment (2)
- Respondent a medical professional (2)

After hospital (n = 3)

- learned baby had failed test (2)

Never told (n = 17)

- 14 of which are "unknown" results
- never told and learned from survey (2)

Table 3. *Frequencies, Hearing Screening Refusal*

Did you refuse your baby's hearing screening?	Frequency	Percent
<i>No</i>	1292	98.8%
<i>Yes</i>	16	1.2%
Total	1308	100%

Hearing Test Results

Parents were asked to indicate how they were told of their baby's results as well as how they understood the results of the test. Based on their responses, surveys were coded using the following codes:

- PA: Passed
- RNR: Referred (but no follow-up test)
- RSP: Referred, passed re-screen
- HL: Hearing Loss
- HLP: Hearing Loss Possible
- NS: Not Screened
- UNK: Unknown results (either unclear or parents did not know)

The results as coded are provided in Table 4, and the compiled data regarding hearing test results is located in Table 5. While some of the numbers are small, the percent of those referred and with hearing loss are representative of the percent of newborns in the total population, during this time period who referred (approximately 3%) and have hearing loss (approximately 0.2%)

Table 4. *Hearing Test Results, Coded*

Code	Frequency	Percent
Hearing loss	5	0.4%
Hearing loss possible	5	0.4%
Not screened	20	1.5%
<i>Passed</i>	<i>1109</i>	<i>84.3%</i>
Referred, no follow-up	3	0.2%
Referred, passed screening	50	3.8%
Unknown	124	9.4%

Table 5. *Respondents' Reported Hearing Test Results*

	Frequency	Percentage
How first told of the results (<i>n</i> = 1,254)		
<i>Staff told me before I went home</i>	<i>1012</i>	<i>85%</i>
Card before I went home	78	6.2%
Staff told me after I went home	9	0.7%
Letter mailed home	14	1.1%
I was never told the results	85	6.8%
Results of initial hearing test (<i>n</i> = 1,177)		
<i>Passed</i>	<i>1110</i>	<i>94.3%</i>
Referred for more testing	59	5.0%
Don't know	8	0.7%
How you understood the results (<i>n</i> = 1,169)		
<i>My baby did not have hearing loss</i>	<i>1065</i>	<i>91.1%</i>
Hearing loss was possible,	80	6.8%

but <i>unlikely</i>		
Hearing loss was <i>possible</i>	9	0.8%
Hearing loss was <i>very likely</i>	0	0%
Hearing loss was <i>certain</i>	1	0.1%
Did not understand results	14	1.2%

Feedback on and Satisfaction with Baby's Screening

Parents were asked to provide feedback on the screening process as well as indicate their level of satisfaction with the services they received. Respondents indicated their level of agreement with a series of statements regarding their perception and experience with their baby's screening. Responses were based on a 5-point Likert scale (1 = definitely disagree; 5 = definitely agree). As shown in Table 6, the people doing the hearing screening were rated favorably. It's important to note that 26 %– 48% of respondents noted they were “not sure” when asked to rate the screening services.

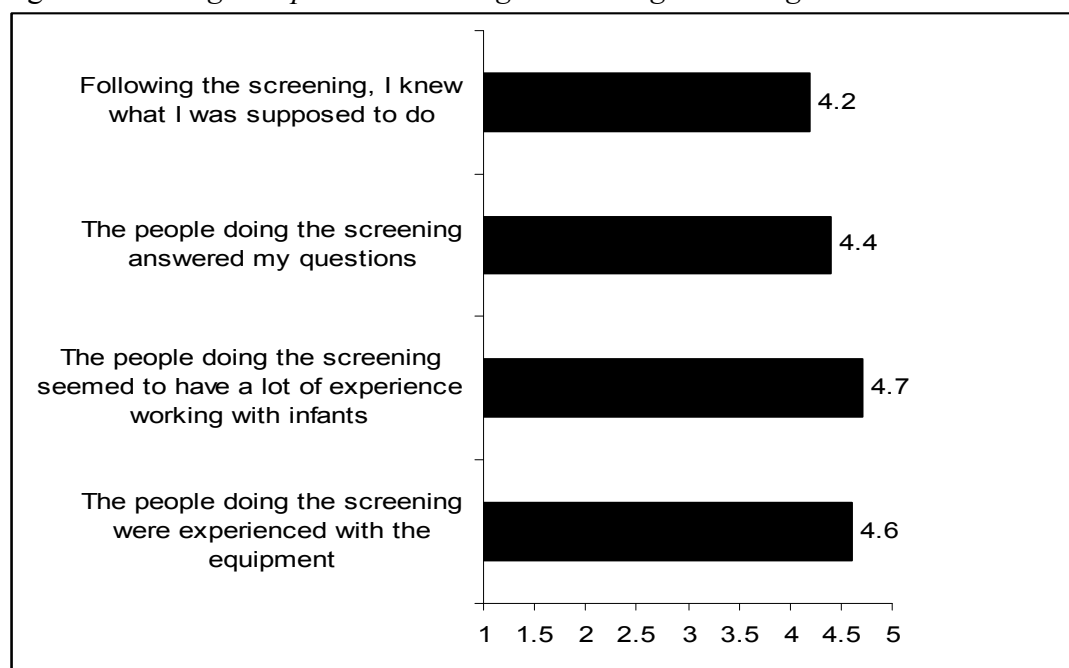
Table 6. *Respondents' Feedback on Hearing Screening Services*

	Mean 1 = definitely disagree; 5 = definitely agree	Standard Deviation	% Not Sure
a. The people doing the screening were experienced with the equipment	4.6**	.791	48%
b. The people doing the screening seemed to have a lot of experience working with infants	4.7*	.70	30%
c. The people doing the screening answered my questions	4.4	1.12	27%
d. Following the screening, I knew what I was supposed to do	4.2	1.31	26%

* = significantly higher than a, c & d ($p < .01$)

** = significantly higher than c & d ($p < .01$)

Figure 1. *Average Respondents' Rating on Hearing Screening Services*



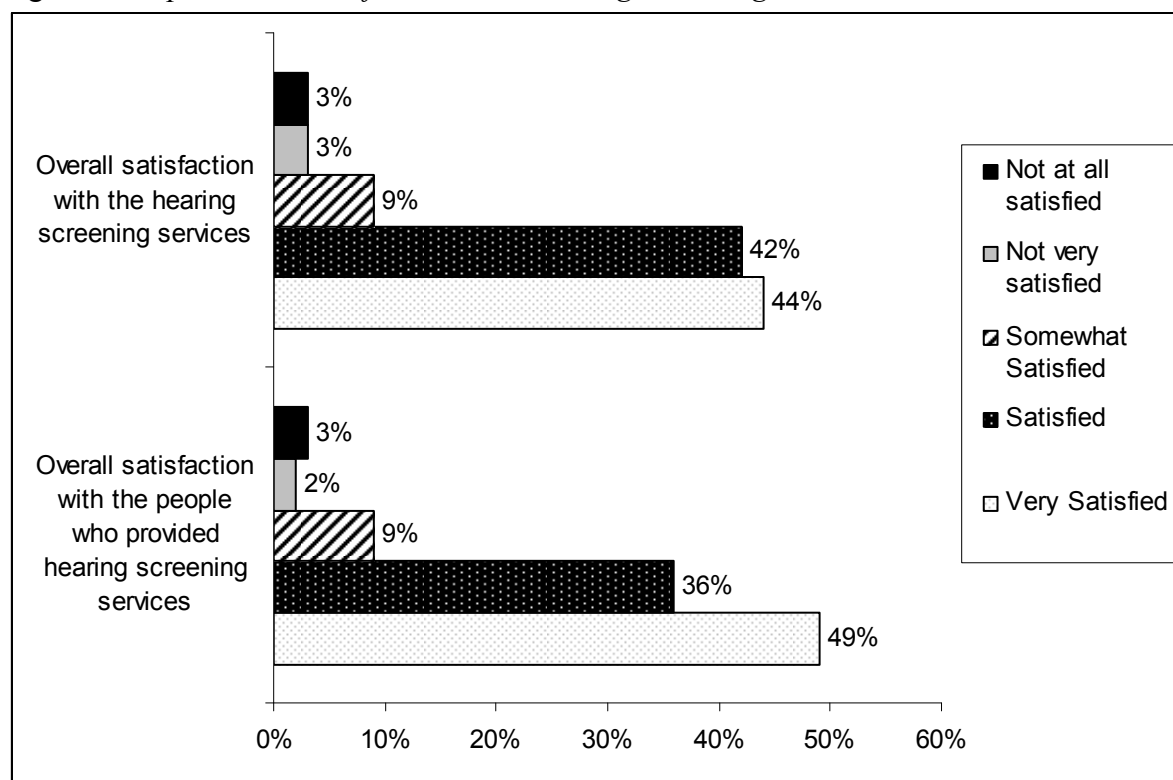
Approximately 86% of respondents were satisfied to very satisfied with the hearing screening services they received. The average ratings were 1.7 and 1.8 indicating that respondents were relatively satisfied with the people providing the hearing screening services as well as the services overall. Please note that a *lower* number indicates a *higher* level of satisfaction.

Table 7. *Respondents' Satisfaction with Hearing Screening Services*

	Mean 1 = very satisfied; 5 = not at all satisfied	SD	Very Satisfied – Satisfied (%)	Somewhat to not very satisfied (%)	Not at all satisfied (%)
a. Overall satisfaction with the <i>people</i> who provided hearing screening services	1.73*	.924	85.7%	11.5%	2.8%
b. Overall satisfaction with the hearing screening <i>services</i>	1.80	.922	85.6%	11.4%	2.9%

* = significantly lower than b ($p < .01$)

Figure 2. *Respondents' Satisfaction with Hearing Screening Services*



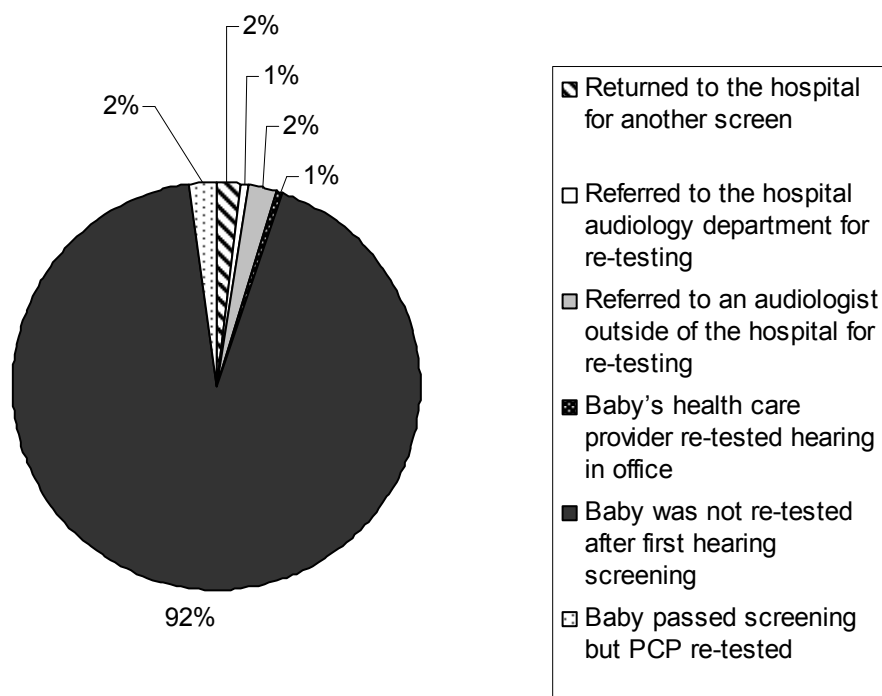
Screening Next Steps

Respondents were asked to identify what happened following their baby's screening. As noted in the following table, the majority of participants noted that their baby was not re-screened.

Table 8. *Percent of Respondents Noting Screening Follow-up*

After your baby's screening, what happened next?	Frequency	Percentage
Returned to the hospital for another screen	23	1.9%
Referred to the hospital audiology department for re-testing	9	0.7%
Referred to an audiologist outside of the hospital for re-testing	24	2.0%
Baby's health care provider re-tested hearing in office	9	0.7%
<i>Baby was not re-tested after first hearing screening</i>	1138	92.6%
Baby passed screening but PCP re-tested	23	2.1%

Figure 3. *Percent of Respondents Noting Screening Follow-up*



Results: Hearing Re-Testing

Respondents noting that their child's hearing was re-tested were asked to describe how they learned about their results, their perception of the results, and their overall satisfaction with the re-testing process. These results are summarized below.

Table 9. *Respondents' Perception of Hearing Re-Test Results, (n = 68)*

	Frequency	Percentage
How were you first told of the results of re-testing? (n = 68)		
<i>Staff told me before I went home</i>	60	88.2%
Staff told me after I went home	1	1.5%
Letter mailed home	2	2.9%
Other	5	7.4%
<i>Not re-tested yet</i>	4	5.8%
How you understood the results (n = 66)		
<i>My baby did not have hearing loss</i>	50	75.8%
Hearing loss was <i>possible</i> , but <i>unlikely</i>	9	13.6%
Hearing loss was <i>possible</i>	4	6.1%
Hearing loss was <i>very likely</i>	1	1.5%
Hearing loss was <i>certain</i>	1	1.5%
Did not understand results	1	1.5%

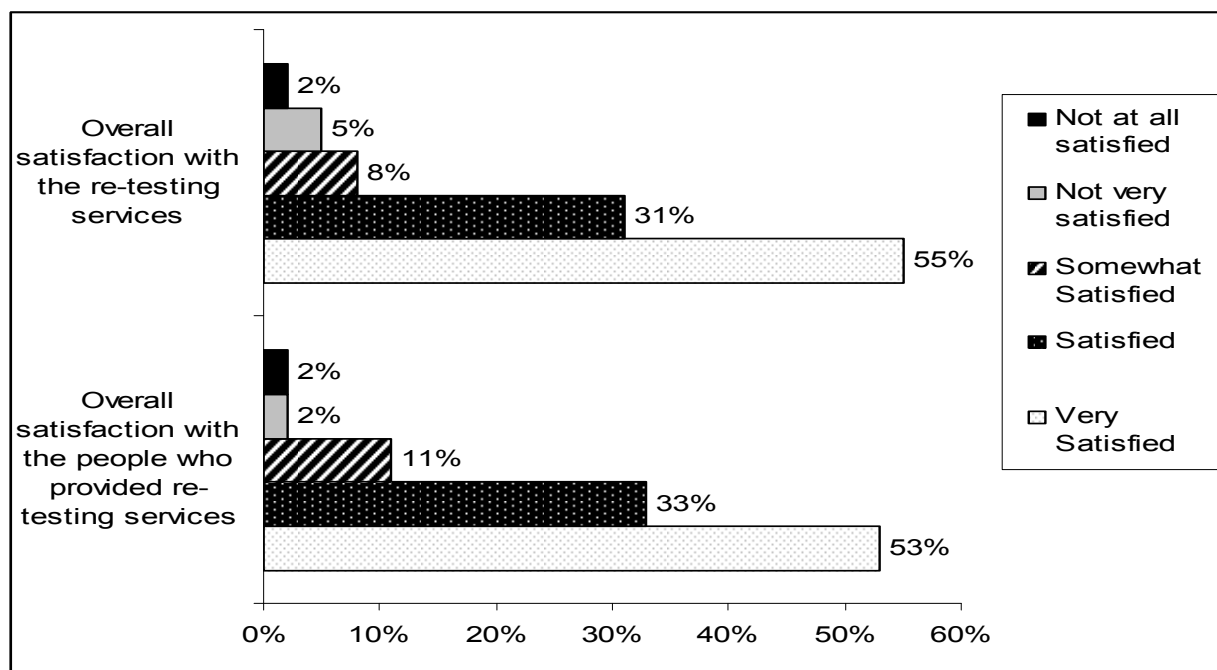
Overall Satisfaction with Re-Testing

Respondents were asked to rate their level of satisfaction with the hearing re-testing process. Responses were based on a 5-point Likert (1 = very satisfied; 5 = not at all satisfied). As shown in Table 10 and Figure 4, respondents noted a high level of satisfaction with the re-testing services and people who provided the services.

Table 10. *Respondents' Satisfaction with Re-Testing, (n = 64)*

<i>n</i> = 64	Mean 1 = very satisfied; 5 = not at all satisfied	SD	Very Satisfied – Satisfied (%)	Somewhat to not very satisfied (%)	Not at all satisfied (%)
Overall satisfaction with the <i>people</i> who provided re-testing services	1.66	.86	86%	12.5%	1.6%
Overall satisfaction with the re- testing <i>services</i>	1.67	.93	86%	12.5%	1.6%

Figure 4. *Respondents' Satisfaction with Re-Testing.*



Results by Code

The following section provides an overview of the survey results by hearing test result code. As noted previously, surveys were coded based on respondents' answers to questions regarding the results of their baby's test as well as screening follow-up (i.e., "after the screening, what happened next?"). As these codes reflect the respondents' perception of and answer to the questions, some of the results may appear inconsistent; when applicable these inconsistencies are shaded.

Table 11. *Respondent Demographics by Code*

	Passed (n = 1109)	Referred (n = 53) (Passed re-test or No Follow-up)	Hearing Loss (n=10)	Not Screened (n = 20)	Results Unknown (n=124)
Relationship to Child					
Mother	1079 (98%)	53	9 (90%)	19	118 (97%)
Father	26 (2%)	--	1 (10%)	1	4 (3%)
Race/ethnicity					
Caucasian	1006 (92%)	48	8 (80%)	18 (90%)	107 (88%)
African- American	6 (0.5%)	--	--	--	--
Hispanic	10 (0.9%)	--	1 (10%)	--	--
Asian- American	11 (1%)	1	--	--	4 (3%)
Native American	12 (1 %)	1	--	--	4 (3%)
Other	46 (4%)	1	1 (10%)	2 (10%)	7 (6%)
Education					
Less than some high school	--	--	--	--	1 (0.8%)
Some high school	45 (4%)	1	--	3 (15%)	8 (7%)
High School Grad	198 (18%)	9	3 (30%)	1 (5%)	19 (15%)
Some college or vocational	240 (22%)	14	4 (40%)	3 (15%)	36 (29%)
College degree	455 (41%)	22	2 (20%)	10 (50%)	45 (37%)
Graduate degree	166 (15%)	7	1 (10%)	3 (15%)	14 (11%)
County					
Androscoggin	82 (9%)	3 (7%)	1 (10%)	1 (6%)	7 (7%)
Aroostook	38 (4%)	1 (2%)	--	--	13 (13%)
Cumberland	225 (24%)	7 (16%)	3 (30%)	4 (22%)	28 (29%)

Franklin	23 (3%)	--	--	--	2 (2%)
Hancock	36 (4%)	3 (7%)	--	2 (22%)	2 (2%)
Kennebec	81 (9%)	8 (19%)	2 (20%)	--	4 (4%)
Knox	20 (2%)	1 (2%)	--	1 (6%)	4 (4%)
Lincoln	29 (3%)	--	1 (10%)	--	1 (1%)
Oxford	39 (4%)	1 (2%)	--	1 (6%)	4 (4%)
Penobscot	120 (13%)	5 (12%)	1 (10%)	2 (11%)	6 (6%)
Piscataquis	9 (1%)	--	--	--	--
Sagadahoc	28 (3%)	1 (2%)	--	1 (6%)	1 (1%)
Somerset	24 (3%)	--	--	--	3 (3%)
Waldo	34 (4%)	1 (2%)	--	1 (6%)	5 (5%)
Washington	32 (4%)	1 (2%)	--	--	--
York	103 (11%)	12 (28%)	1 (10%)	3 (17%)	18 (18%)
Out of Maine	3 (0.3%)	--	--	--	--
Insurance Coverage					
MaineCare	347 (32%)	17 (32%)	3 (30%)	4 (27%)	53 (45%)
Private insurance	649 (59%)	32 (58%)	5 (50%)	4 (27%)	56 (47%)
Self-pay	22 (2%)	2 (4%)	--	4 (27%)	4 (3%)
MaineCare & Private	40 (4%)	2 (4%)	1 (10%)	1 (7%)	1 (0.8%)
MaineCare and self-pay	6 (0.5%)	--	1 (10%)	2 (13%)	1 (0.8%)
Private & Self-pay	34 (3%)	1 (2%)	--	--	4 (3%)

Hearing Results by Code

As shown in Table 12, most respondents were told their baby's results before leaving the hospital. In addition, of those parents with babies who referred, most re-screened at the hospital. Following the re-test the majority of these respondents noted that their baby most likely did not have hearing loss. Of those parents of babies with hearing loss, most were referred to an audiologist for re-testing.

Table 12. *Hearing Test Results by Code*

	Passed (n = 1109)	Referred (n = 53) Passed re-test or No Follow-up	Hearing Loss (n = 10)	Unknown (n = 124)
How first told of the results				
Staff told me before I went home	946 (86%)	48 (91%)	8 (80%)	10 (8%)
Card before I went home	77 (7%)	--	--	1 (0.8%)
Staff told me after I went home	9 (0.8%)	--	--	--
Letter mailed home	14 (1%)	--	--	--

I was never told the results	3 (0.3%)	1 (2%)	1 (10%)	78 (63%)
Told at hospital and received card before going home	50 (5%)	4 (7%)	1 (10%)	--
Results of initial hearing test				
Passed	1107 (100%)	3 (6%)	--	1 (0.8%)
Referred for more testing	--	49 (92%)	8 (100%)	1 (0.8%)
Don't know	--	--	--	8 (6.4%)
How you understood the results				
My baby did not have hearing loss	1046 (95%)	11 (21%)	1 (14%)	7 (6%)
Hearing loss was <i>possible</i> , but <i>unlikely</i>	47 (4%)	31 (58%)	2 (29%)	--
Hearing loss was <i>possible</i>	1 (0.1%)	5 (9%)	3 (43%)	
Hearing loss was <i>very likely</i>	--	--	--	
Hearing loss was <i>certain</i>	--	--	--	--
Did not understand results	8 (0.7%)	5 (9%)	1 (14%)	--
What happened after baby's screening				
Returned to the hospital for another screen	2	20 (38%)	1 (10%)	--
Referred to hospital audiology for re-test	--	8 (15%)	1 (10%)	--
Referred to outside audiologist for re-test	--	16 (30%)	7 (70%)	1 (0.8%)
Baby's health care provider re-tested hearing in office	27	6 (11%)	1 (10%)	1 (0.8%)
My baby was not re-tested	1060	3 (6%)	--	75 (60%)

Satisfaction with Screening Services

The following table identifies respondents' level of satisfaction by hearing code. Based on the average rating, those parents who had a child diagnosed with hearing or whose results are unknown, tended to indicate a lower level of satisfaction with the screening process. This is most clear in their satisfaction with the level of information they received (i.e., having their questions answered, knowing what to do next).

Table 13. *Respondents' Satisfaction with Hearing Screening Services, by Code*

	Passed	Referred	Hearing Loss	Unknown
Satisfaction with initial hearing screening: Mean (Standard Deviation)				
(1 = definitely disagree; 5 = definitely agree)				
The people doing the screening were experienced with the equipment	4.6 (.71)	4.0 (1.2)	4.1 (1.1)	4.1 (1.2)
The people doing the screening seemed to have a lot of experience working with infants	4.7 (.7)	4.5 (0.7)	4.6 (0.8)	4.6 (0.6)
The people doing the screening answered my questions	4.4 (1.1)	4.2 (1.2)	3.5 (1.4)	3.3 (1.6)

Following the screening, I knew what I was supposed to do	4.2 (1.3)	4.4 (1.0)	3.9 (1.4)	2.6 (1.7)
Overall Satisfaction with Hearing Screening: Mean (Standard Deviation) 1 = very satisfied; 5 = not at all satisfied				
Overall satisfaction with the <i>people</i> who provided hearing screening	1.6 (0.8)	1.9 (1.0)	2.3 (1.2)	2.6 (1.2)
Overall satisfaction with the hearing screening <i>services</i>	1.7 (0.8)	2.1 (0.9)	2.6 (1.4)	2.8 (1.2)
Overall Satisfaction with Re-Testing: Mean				
Overall satisfaction with the <i>people</i> who provided re-testing services	1.6	1.5	2.5	--
Overall satisfaction with the re-testing <i>services</i>	1.6	1.6	2.4	--

Resources and Additional Screening Program Feedback

In an effort to evaluate the dissemination of various education materials, the survey included a series of questions which asked the respondents to identify the materials they have received. These responses are included in the following table.

Table 14. *Educational Information Received*

	Passed	Referred	Hearing Loss	Unknown
Received information from the hospital				
Yes	369 (37%)	18 (34%)	4 (44%)	19 (23%)
No	366 (34%)	18 (34%)	5 (56%)	42 (51%)
Don't know	313 (29%)	13 (25%)	--	22 (27%)
Received information from Audiologist				
Yes	n/a	2 (4%)	3 (50%)	n/a
No	n/a	--	2 (33%)	n/a
Don't know	n/a	--	1 (17%)	n/a
Received information from Early Childhood Family Services				
Yes	n/a	1 (2%)	3 (75%)	n/a
No	n/a	--	--	n/a
Don't know	n/a	--	1 (25%)	n/a

Babies with Hearing Loss: Early Intervention Services

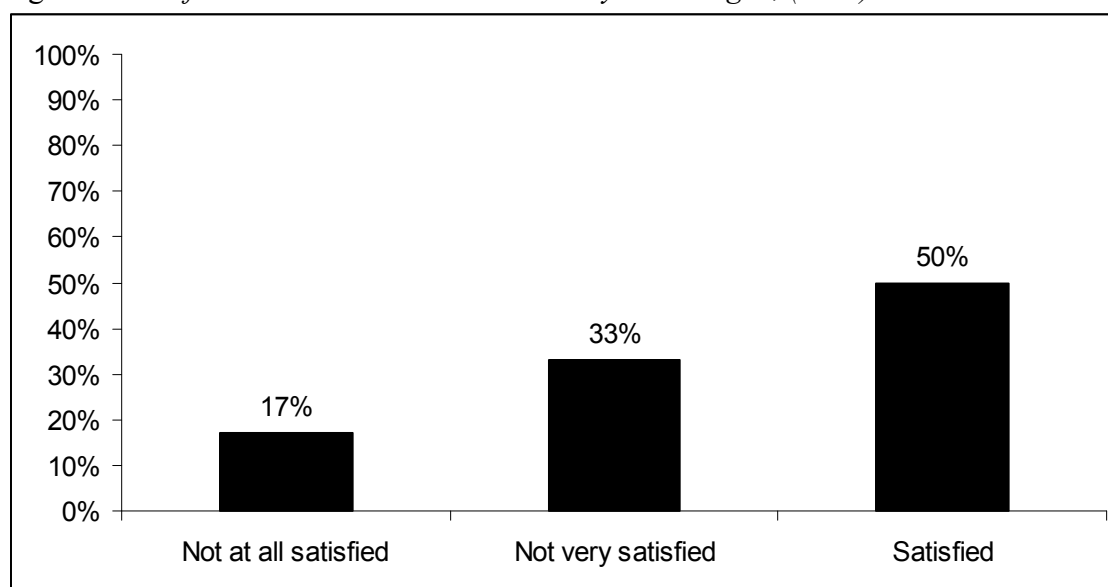
The following section provides an overview of the responses parents of a baby with hearing loss provided regarding follow-up and early intervention services. While this sample is very small, the percentage is comparable to the overall percentage of parents in Maine who have a baby identified with hearing loss each year.

The following table shows the number of times respondents have visited the audiologist. As shown in Figure 5, 50% of those respondents rating their satisfaction with the services they have received from the audiologist were satisfied, the remaining half noted that they were not satisfied.

Table 15. *Early Intervention Services, Babies with Hearing Loss, (n = 8)*

Number of visits to audiologist	Frequency	Percentage
0 times	2	25%
2 -3 times	3	38%
4 -5 times	1	13%
6 or more times	2	25%

Figure 5. *Satisfaction with Services Provided by Audiologist, (n= 6)*



The majority (57%) of those respondents with babies diagnosed with hearing loss indicated that they are or were receiving support from early intervention providers. Reasons given for their baby **not** receiving such support included:

- The audiologist told me my baby did not need early intervention services (1)
- I have not been contacted about early intervention services (1)
- Other: “She had surgery for tubes to be placed and now we are going to screen her again for hearing loss.” (1)

Finally, respondents were asked to list and rate up to four services their baby has or is receiving to help with his or her hearing loss. Only four respondents answered this question and their responses are summarized in Table 16. The age when service began ranged from three to nine months with an average of seven months. The average quality rating for services received was 1.3 based on a five -point scale (1 = Excellent; 5 = Poor). Thus, the quality of early intervention services was rated high.

Table 16. *Type of Early Intervention Services Received*

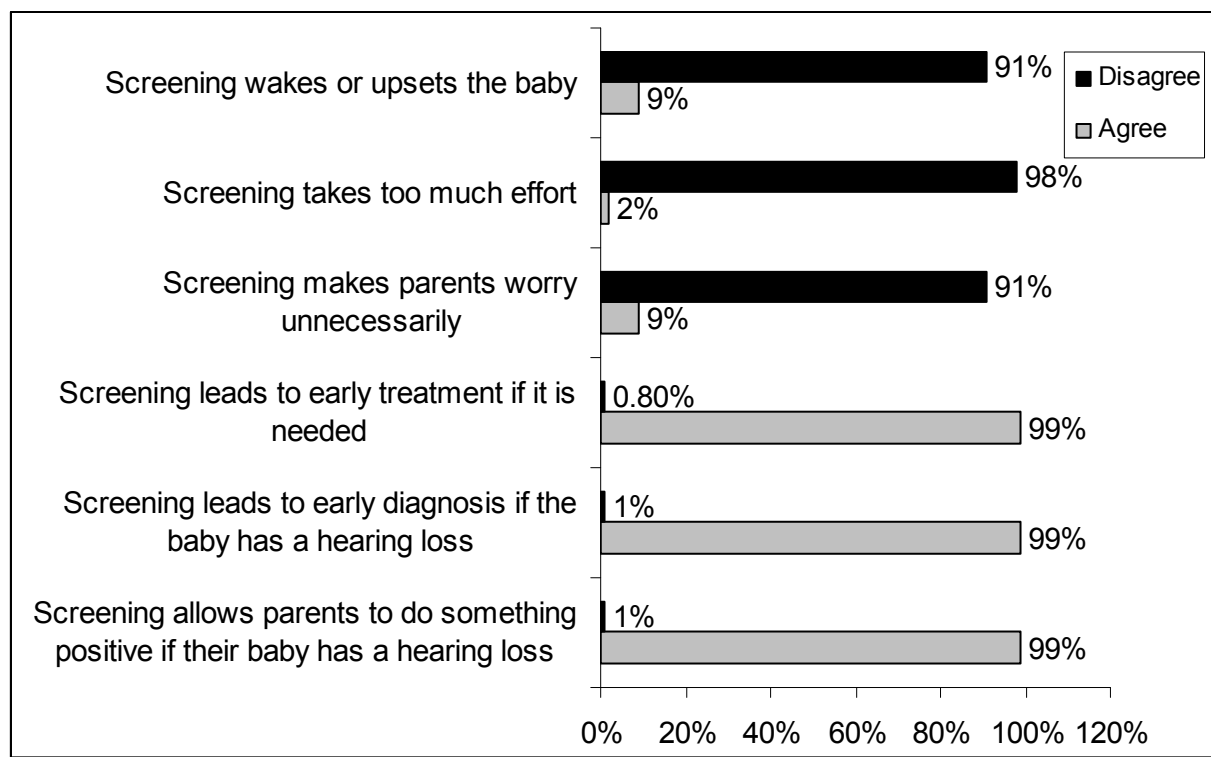
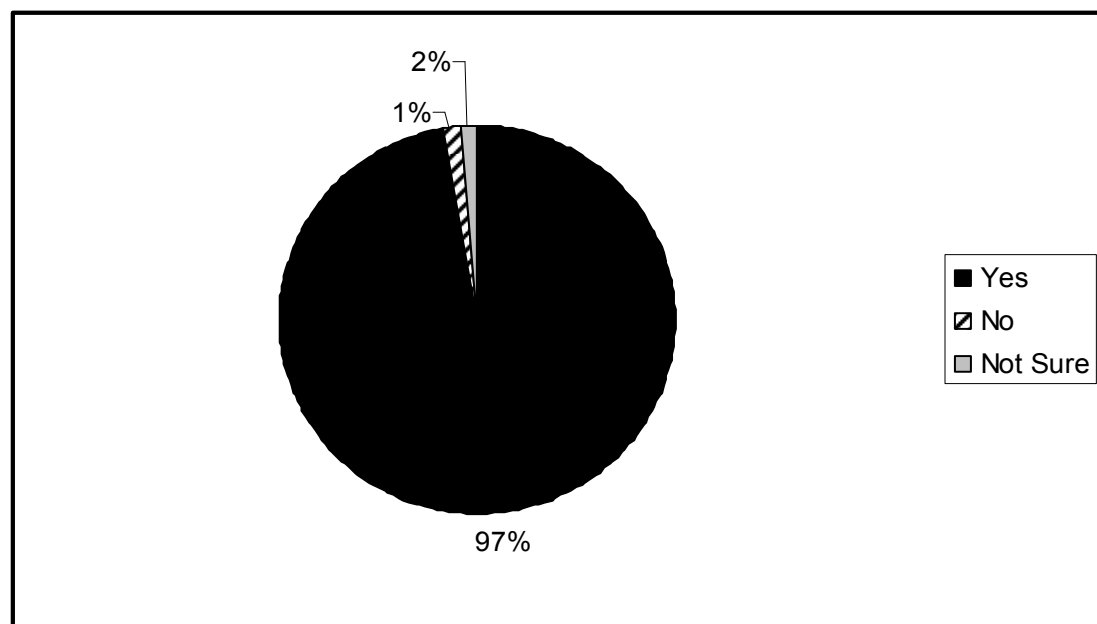
Agency	Type of Service	Frequency
Baxter School for the Deaf	--	1
Child Development Services	Service coordination Evaluations Early intervention Physical therapy Behavioral assessment	4
hear ME Now!	Behavioral assessment Speech therapy Developmental therapy	2
Early Childhood & Family Services	Support, information	1
Maine Educational Center for the Deaf and Hard of Hearing	Education Support Service coordination	2
Easter Seals of Maine	Developmental	1
North Hearing and Speech	Audiologist	1

Attitudes about Newborn Hearing Screening

The final section of the survey included questions regarding parents' attitudes toward the newborn hearing screening program. The majority of respondents in each code group and overall held favorable attitudes toward newborn hearing screening. Moreover, 97% of respondents noted that they would want to have any future children screened as well. These results are shown in Table 17 and Figures 6 and 7.

Table 17. *Attitudes toward Hearing Screening, by Code*

	Passed	Referred	Hearing Loss	Unknown
Screening allows parents to do something positive if their baby has a hearing loss				
Agree	1085 (99%)	51 (98%)	10 (100%)	111 (98%)
Disagree	9 (0.8%)	1 (2%)	--	2 (2%)
Total	1094	52	10	113
Screening leads to early diagnosis if the baby has a hearing loss				
Agree	1091 (99%)	51 (98%)	10 (100%)	108 (96%)
Disagree	7 (0.6%)	1 (2%)	--	5 (4%)
Total	1098	52	10	113
Screening leads to early treatment if it is needed				
Agree	1087 (99%)	51 (100%)	10 (100%)	111 (98%)
Disagree	8 (0.7%)	--	--	2 (2%)
Total	1095	51	10	113
Screening makes parents worry unnecessarily				
Agree	78 (7%)	13 (25%)	2 (22%)	16 (14%)
Disagree	996 (92%)	38 (75%)	7 (78%)	95 (86%)
Total	1074	51	9	111
Screening takes too much effort				
Agree	17 (2%)	2 (4%)	--	4 (4%)
Disagree	1076 (98%)	50 (96%)	10 (100%)	108 (96%)
Total	1093	52	10	112
Screening wakes or upsets the baby				
Agree	81 (8%)	8 (15%)	2 (20%)	10 (9%)
Disagree	964 (92%)	44 (85%)	8 (80%)	96 (91%)
Total	1045	52	10	106
If you had another baby would you want them screened?				
Yes	1084 (98%)	48 (92%)	10 (100%)	114 (97%)
No	6 (0.5%)	2 (4%)	--	--
Not sure	12 (1%)	2 (4%)	--	3 (3%)
Total	1102	52	10	117

Figure 6. *Attitudes toward Hearing Screening, Total Sample*Figure 7. *Percentage of Respondents Who Would Have Another Baby Screened*

Results: Not Screened

Twenty respondents (2%) noted that their baby did not have a hearing screening. Of these, 15 (75%) refused a hearing screening (one additional respondent refused initial screening but had baby screened on recommendation of pediatrician).

Table 18. *Not Screened: Demographics by Refusal*

	Refused (<i>n</i> = 16)	Not Refused (<i>n</i> = 5)
Relationship to Child		
Mother	16 (100%)	4 (80%)
Father	--	1 (20%)
Race/ethnicity		
Caucasian	15 (94%)	4 (80%)
Other	1 (6%)	1 (20%)
Education		
Less than some high school	--	--
Some high school	1	2 (40%)
High School Grad	--	1 (20%)
Some college or vocational	2	1 (20%)
College degree	9	1 (20%)
Graduate degree	4	--
County		
Androscoggin	1 (6 %)	--
Aroostook	--	--
Cumberland	3 (19%)	1 (20%)
Franklin	--	--
Hancock	3 (19%)	1 (20%)
Kennebec	--	--
Knox	1 (6%)	--
Lincoln	--	--
Oxford	1 (6%)	--
Penobscot	1 (6%)	1 (20%)
Piscataquis	--	--
Sagadahoc	1 (6%)	--
Somerset	--	--
Waldo	1 (6%)	--
Washington	--	--
York	2 (13%)	1 (20%)

Explanations for Refusal

Unnecessary/disruptive:

- Did not feel it was necessary. Talked with pediatrician about it.
- Did not want any unnecessary tests done. Did not want to leave or disturb baby. Most “recommended procedures” are disruptive, hearing screening is one of them.
- I wanted very little invasive intervention right after birth especially that which was stimulus oriented. I wanted her to have stillness & quiet as a just newborn.
- Just didn't feel it was necessary but later did it on request of our pediatrician
- Just didn't think it was necessary. You can tell whether or not baby can hear
- Not necessary
- She had been through enough.
- Testing of any kind undesired, unless necessary. Natural childbirth.
- We wanted the least possible interventions and decided it was unnecessary

Home birth/Healthcare provider observed hearing

- We did not have it done at birth because our son was born at home and I never got around to getting any of my children (3) tested at or after birth
- We had a homebirth. My husband and I decided to forgo the screening unless there seemed a problem in our son's hearing.
- Not a refusal, but baby was born at home.
- Healthcare provider was satisfied with the sign's of baby's hearing
- Home birth. My midwife observed our infant, and could see he responded to sound at birth without a machine!
- Homebirth, not necessary
- She was born at home and received no screening.

Table 19. *Knowledge of Hearing Screening, by Refusal*

	Refused	Not Refused
Before admission	4 (27%)	--
While in hospital	4 (27%)	1 (20%)
After hospital discharge	--	--
Not sure	1 (7%)	2 (40%)
Other	6 (40%)	2 (40%)

Other:

From Midwife, prenatal visit (4)

- Had homebirth-told during prenatal visits with midwife
- Midwife informed while pregnant
- Midwives informed me of the option to screen
- with midwife during pregnancy

Did not know about screening, home birth

- We had a midwife [who] attended home birth. We did not have a hearing screening and did not know about screen

Attitudes about Newborn Hearing Screening

Somewhat contradictory, parents who refused to have their newborn's hearing screened at birth still believed screening to be positive and to lead to early diagnosis and treatment. Where they differed from the larger sample was in their belief that screening makes parents worry, takes too much effort, and disrupts the baby. These results are shown in Table 20.

Table 20. *Attitudes toward Newborn Hearing Screening, by Refusal*

	Refused	Not Refused
Screening allows parents to do something positive if their baby has a hearing loss		
Agree	5 (83%)	3 (100%)
Disagree	1 (17%)	--
Total	6	3
Screening leads to early diagnosis if the baby has a hearing loss		
Agree	7 (88%)	2 (67%)
Disagree	1 (12%)	1 (33%)
Total	8	3
Screening leads to early treatment if it is needed		
Agree	7 (100%)	3 (100%)
Disagree	--	--
Total	7	3
Screening makes parents worry unnecessarily		
Agree	4 (44%)	--
Disagree	5 (56%)	2 (100%)
Total	9	2
Screening takes too much effort		
Agree	4 (44%)	2 (100%)
Disagree	5 (56%)	--
Total	9	2
Screening wakes or upsets the baby		
Agree	5 (71%)	--
Disagree	2 (29%)	2 (100%)
Total	7	2
If you had another baby would you want them screened?		
Yes	1 (7%)	3 (75%)
No	10 (71%)	--
Not sure	3 (21%)	1 (25%)
Total	14	4

Qualitative Results

Respondents were provided the opportunity to make suggestions for improvement of the Maine Newborn Hearing Screening Program. The following section includes a summary of the findings related to comments respondents made related to their satisfaction with the screening services they received as well as suggestions for improvement of the program. A full report of qualitative findings, including all verbatim comments, can be provided upon request of the program.

Comments Related to Satisfaction with Screening Services

184 respondents provided additional comments on Question #7 asking them to rate their satisfaction with the people who conducted the newborn hearing screening. Of the 184 respondents, 89% noted that they were not present for, were not aware of or cannot remember the screening. A sample of those comments are noted below:

- Can't answer as I was not present at the screening.
- Did not know who did the screening or that it was being done at the time
- Did not meet who performed screening. As an audiologist I would like to have been invited to observe. I had this opportunity in 2004 with our other child. Perhaps the screener was nervous b/c she knew I was an audiologist. I had to correct the r/l insertion
- Do you mean the nurses? Or are there other people? They are done when she was sleeping so I can't judge the screening services.
- Don't know who did the screening. Just took baby from room and came back and told us he passed
- Don't think there were any follow-up steps since hearing was fine. Really can't remember who did it since it was 8 months ago. I was just told his hearing is fine so don't know anything beyond that
- Have no idea who did screening- I was not offered the chance to go with my baby.
- I'm sure he passed but I don't recall ever having a conversation about the test. I don't recall being given any results.
- I am unsure if the screening was done, if it was done I was not made aware of it. She went to the nursery for a few hours in the night perhaps they did the screening then?
- I didn't really meet them. The nurse brought her back after she spent the night in the NICU and said that she has passed her screening test without any problems.
- Wasn't informed she was going to have one. Until she failed.
- Not quite sure who did the screening. If it was our pediatrician-we are fully confident in her skills. Wish I had the opportunity to go watch, so the staff could explain the test, and I had the opportunity to ask questions, I had to go on what the hospital said.

A few respondents gave specific feedback regarding their experience with newborn hearing screening. A commonly noted area of improvement included updating the equipments and increasing the knowledge of staff.

- 1st birth '05 they were great...'07 seemed more inexperienced.
- Didn't seem to know how to operate equipment took several times and different machine.
- Referring to test after discharge at [hospital audiology department]. Equipment seemed outdated, 'acted up' tech a little matter of fact, not as gentle as I'd like. Upset by taping/untaping/retaping the pain it caused my baby. No one prepared me for this. Tech lacked bedside manner.
- Broken machine at [hospital].
- This is the hospitals responsibility to hire adequate personnel
- I think our Dr. should have done the screening. Not a random nurse.

Positive feedback included:

- Very satisfied with [nurse] at [hospital].
- Very sweet people
- I was VERY pleased with all my treatment at [hospital] so if a screen was done I'm sure it was excellent.

Finally, several respondents ($n = 7$) noted that they had never received the results or had inadequate follow-up (i.e., not given an instructions)

Suggestions for Improving Newborn Hearing Screening Process

Provide additional information. The most commonly noted suggestion (over 100 responses from all categories of screening result) included the need to provide more information regarding the process of screening, what it entails, what the results mean, and actions needed for follow-up (if needed). Moreover, many respondents suggested providing education about newborn hearing screening at prenatal visits and birthing classes, including sending information to “homebirth midwives.” Selected quotations are provided below.

Additional Information Provided

- Although this was my 3rd baby and I know what to expect-there was very little discussion about the hearing test other than they were going to do one. Then once it was done all I received was a slip saying she passed the test. No one spoke about why it should be done, how long it takes, who does it, etc...
- Be more informative about how they do the screening and to give a better understanding of how they know if the baby has a hearing loss
- Better info to all birthing centers and midwives to get word out on hearing screening and knowledge regarding hearing loss
- Emphasize the positive aspects of early screening
- Explain what the screening process includes, what is the screening process. I also do not recall being asked if I wanted it done.
- Giving an educational pamphlet to parents in the hospital that explains what hearing screening is all about: i.e., description of the procedures, who will be doing it, why? What to do if results are abnormal.
- Have someone explain the process better, why, if any, info on so many children have hearing loss. If there is anything to look out for later in development.
- Have the doctor explain everything about the hearing before and after the baby's screening, even if the baby passes to make sure the parent's understand.

- My only suggestion is that when baby fails the first screening, they need to explain better the different reasons. For instance, my daughter woke up and disrupted the machine, which caused it to fail her the first time. Instead of explaining that situation first, they just said she FAILED, which caused unnecessary stress for myself & father
- It was never explained to me why both ears needed retesting. My baby's left ear was fine, but she needed both retested. Given how stressful this process was, it seemed unnecessary to retest both ears. When I asked the tester, just said 'state law' & that's it. No medical explanation. Please do something to minimize the # of times the probes need to be ripped off & reattached
- Tell the mothers & fathers of the babies the results of the tests. Unsatisfied with hearing screening services because we weren't told anything.

Additional suggestions related to wanting more information included increased screening follow-up, as noted in the following quotes. The respondents included one parent with a child with hearing loss and the remaining had children who passed their screening.

Increased Screening Follow-up

- Provide outreach to parents to ensure appointments are made with an audiologist to confirm loss (parent of child with hearing loss)
- Our baby was taken at hospital from delivery for hearing test and all we know is she passed. Nothing else. No paperwork. She has never been tested since delivery. Every pediatrician visits they don't test hearing only visible ear exams.
- I believe that there should be a coordinator going over results with parents and answering any questions. The nurses could not answer my questions or concerns. I told every nurse I had from before my baby was born to before I left the hospital that I have a child with hearing impairment and that I wanted this conveyed to the assessor so that he/she could maybe do additional tests for hearing loss with the baby. No one could tell me when he was going to be tested either. Nobody came to speak with me or could answer my concerns or questions. I felt frustrated because I made several attempts to make sure that the technician knew my concerns. I left the hospital skeptical with the results of the hearing tests. I will probably have him tested soon.
- I received nothing regarding results and no knowledge of rescheduling for a rescreening.
- Good idea to know if there was any problems you'd be set up before you get home.
- I was not aware of any follow-up procedures so inform parents of anything else they may have to do
- The screening process itself was smooth and communication at the hospital was great. We just weren't sure how long the test was valid for, and when to test again down the road.

Parents present at screening. The second most commonly cited suggestion (approximately 90 responses) included allowing or asking the parents to be present at the screening and to encourage their involvement. Respondents often noted that they were not present or asked to attend as the screening was done at night. Respondents were primarily parents of babies who passed their screening. A sampling of quotes is provided below.

Parents Present at Screening

- Have the parents be present and involved when the baby is being tested. This way they can see the test being done-learn how the baby reacts if there is any problems they can see it themselves.-Also, it gives opportunities to ask questions. If you don't see it you may not know what to ask. Also, Education for families what to be looking for[hearing loss]. It usually is easier for people to experience things or see it, than just being told.
- You asked questions that would need parent present. We weren't asked to be there while test was given, you might want to give that option.
- The nurses at the hospital took the baby from me to test her hearing. I would have preferred to be present at the screening.
- Screening was performed at night and did not see how it was performed. Would have preferred to see it done. Very happy that they performed it though.
- The parents holding their babies during screening be the rule, not the exception.
- The parents should be there when they do it because they don't always. With my first I was there and my second they did it without me there.
- The hearing screening was performed while my baby was in the nursery. I wish I had been present while they did it. I had told them they could do it but now I just wished I had watched.
- Maybe allow the mom or dad to be present during the screening process. We don't really know how or what was done, but were just told by the nurse that our baby passed which made us very happy!
- Let parents be more involved. Screening usually done at night, nurse takes baby and you are informed of nothing. *(unknown results)*

Logistics of screening process. A common theme stated by parents from all categories of results related to the logistics of the screening. Primarily, suggestions included involving the parents in the timing of the screening, not doing the screening in the middle of the night, being gentle and quiet with the infant, and having the baby's physician or audiologist conduct the screening. Additionally related to this theme was the suggestion to improve the equipment used to screen. Most respondents making this suggestion experienced "faulty" equipment during their baby's screening which often caused their baby to fail the test. These responses are summarized below.

Screening Logistics

- When my son was at [hospital] in the NICU, they did his testing and I believe that the NICU is not a good atmosphere to do the screening of one child. All the sounds, I believe made the testing hard, and we went to the audiologist for nothing, I believe. *(infant diagnosed with hearing loss)*
- Give out a pamphlet describing the procedure or have it done at the 1 mo peds visit. The most important thing the baby needs to do while in the hospital after deliver is rest and bond w/mommy &daddy *(infant not screened)*

Passed:

- Does it have to happen so soon & in the middle of the night? I had no idea what was happening, a nurse woke us up at 3AM the 1st night of my daughter's life & took her out of my room for a screening test. Anything that's not life or death can wait until the next morning I would think! Don't underestimate the incredible exhaustion/stress/euphoria of the first night w/a new baby. Please be more respectful of all three.
- Doing the screening in the room not the nursery due to the volume level of the nursery.
- Have the individuals reporting the information act like it is important. The people who reported to me that my daughter's hearing was fine said it nonchalantly after my asking a few times!

- I'm not sure why the hearing test was done during the middle of the night. It was OK. I was up, maybe informing parents if it is preferred to do it during a quieter time in the department vs whenever the nurse has time to do the screening.
- Feel that newborn hearing screening should be done by certified audiologists and not other ancillary staff (ie RN/LPN). Audiologists are highly trained in this area and would lead to less errors.
- They did my baby's test at 2 am which seemed unnecessary, we were trying to sleep and they didn't explain anything to me at [hospital]. I would have it done by our pediatrician in the future so we're not disrupted.

Referred:

- While in the hospital-it was fine. But when I took my baby to the audiology dept-[clinic]-I suggest: prompt service-it's very difficult to keep baby asleep if I have to wait 30 min's after our scheduled appt to be seen. Also, PLEASE have the staff wear quiet shoes-every time the woman walked-the noise from her shoes onto the floor woke my baby up.
- I had to wait until my son was 6 months old to find out that his hearing was fine, I worried the WHOLE time. I think that the people that perform the hearing tests need to be taught how to do them better. Both at the hospital and at [XX.] I was told my son had to be completely quiet and completely still in order for the test to be done correctly. The audiologist at the last place we went to said that wasn't true at all and was able to test my son and find that his hearing is fine. I wish I would have gone there first so that I didn't have to worry for those six stressful months.
- I think the family's primary care giver should do the test AND give the results.
- I would not do hearing screen again when baby is 1 or 2 days old. They said fluid can cause screwed results. [my] baby passed on 3rd test, they said fluid in ear.

Faulty Equipment

- Give the hospitals the best equipment. My daughter has been tested several times some inconclusive due to faulty machines/environmental disturbances. (*infant diagnosed with possible hearing loss*)
- A year ago-when my daughter was screened- the nurse was having a difficult time getting the equipment to work properly.
- I would suggest that every hospital in Maine is required to have modern equipment used to test every infant's hearing. At [hospital] several of the nurses complained that the screening equipment was outdated and difficult to use. My daughter's first came back as referred, and caused unnecessary worry for 24 hours until her 2nd test was performed. New equipment would have most likely alleviated this problem.
- Please let the patient (parents) know the testing machine is not working which could cause a baby to refer! A lot of unnecessary worrying occurred because we knew our baby referred only to find out the machine was not working.
- The equipment didn't work properly so she failed the 1st test and I worried. Second test was fine. Need to make sure equipment is working properly.
- The equipment was not very user friendly. The nurse, though experienced, had repeated troubles making sure each sensor was working, was placed properly. She had to replace a number of them and it took a long time and child got agitated. Which only made things harder. The equipment should be more user friendly for everyone's sake!
- Be sure the equipment works. Retested screening because the machine failed.
- During our stay in the hospital, there were 8 other infants that had their left ear referred. I question the equipment.
- Very stressful. Isn't there more updated, gentler technology? I was not pleased that she had to be taped/untaped etc because the 'probes were not working' get some new equipment to spare.
- When we had our baby's hearing test, she failed in one ear. As a new mom, I was so upset, losing sleep, etc. The machine was broken at the hospital. I would have appreciated notification of this. Also they sent me to an audiologist after to do in-depth testing whereas they could have done the same test (so much shorter & less expensive) in the hospital or elsewhere and she would have passed easily on a machine that was NOT broken.

Also related to improving the logistics of hearing screening, a few parents suggested making hearing screening mandatory. Moreover, several suggested re-screening hearing at the baby's first well visit with a pediatrician as they felt hearing loss may be missed during the first screen. Finally, only four respondents stated specifically that they had a negative experience. These responses included having "rude" staff to "invasive" equipment.

No improvement needed: Feedback for hospitals. Many respondents ($n = 70$) from all categories of hearing results provided general and specific positive feedback related to their experience with the newborn hearing screening program. Most commented on the importance of hearing screening and early detection. Several parents had hearing loss themselves and cited their experience with the screening program as reducing their anxiety over their child having hearing loss. Some also noted that they saw no room for improvement of the program. A few respondents made specific reference to a hospital staff person or hospital in general. Such comments included their satisfaction with the timing of the test (i.e., during the night) and their overall experience with the hospital. These responses are summarized below.

General Feedback

- Believe that the screening process is a great tool. I am unsure if it upsets the baby to have the screening as I was not present for the testing. I would never refuse anything that is beneficial to my child's wellness and future.
- I would want to know if my child couldn't hear me and I was glad it was part of the process at the hospital.
- The CNA/RN (?) did the test in the evening in the hospital patient room when all was quiet. She explained how it worked and made it interesting for me to take part.
- No suggestions. I think the screening is great! Having a hearing loss myself & finding out at a young age but not at birth. Not sure if it was lost from birth or when, if my parent could have known when I was born maybe things would have been different for me
- All three of my children have been screened, but only one needed to be re-screened. I was grateful for the process thank you!
- Seems like it is done smoothly. I liked how it was done for my daughter. They took her in the middle of the night during a vital sign check so I could rest. (Since it was very hard for them to get her away from me!) I would suggest they continue to do it that way
- None-it was great! I love having the peace of mind knowing my child's hearing is normal as early as possible. The procedure was so gentle my child was practically asleep the whole time.
- Improvement? It was a very simple, quick, painless test... This questionnaire makes me think you're too worried about nothing. It was required for hospital discharge forms, and so probably for everyone else, too. If some babies aren't being screened, they're probably born at home, or an alternate facility I think all hospital-born babies are screened.
- I think the process went great-no suggestions for improvement.
- Keep up the good work keeping Maine's babies healthy and happy.

Feedback for Hospitals

- I'm happy w/ the program. Thank you. [Hospital] was GREAT!!
- I didn't see any issues. [Hospital] is a GREAT place to have a baby
- I had my daughter's hearing test at [Hospital] and they were great about it.
- [Hospital] maternity does a GREAT job!
- [Hospital] is a fantastic place to have a baby!
- [Hospital] staff went above and beyond their duties. I will go there for everything.
- [Hospital] was incredibly good to us and explained everything.
- [Hospital] has been a wonderful experience in the birth of both children.
- I ended up going to an audiologist associated with [Hospital]. They were WONDERFUL!

- But I must say that I LOVED the audiologist associated with [Hospital]. A blessing!
- You have some of the most wonderful staff working at [Hospital]. [Labor and delivery nurse] was my favorite ... she was there for me through my birth even after she was off her shift she stayed with me because I was scared and alone! She made everything so comfortable!

Finally, very few respondents, all of whom have not had their baby's hearing screened stated that a newborn screening test is unnecessary. All of these responses are provided below.

Newborn Test Unnecessary

- I don't understand why a newborn needs to be screened. It is simple to watch a baby and easily notice whether he/she responds to sound. If that first observation resulted in questions about hearing, THEN I would screen a child but not before. I also teach sign language to my children before they talk which lessens frustration for babies. I would rather the state provide education for parents rather than promote across-the-board newborn screening.
- I would only have hearing screened if I could tell the child wasn't hearing accurately.
- No need to screen newborns. Screen later the first year.
- There are too many tests through pregnancy and birth which are unnecessary. A child will be what she will be without all the technology.
- This child was born at home- a planned home birth. Mother is a speech language pathologist who understands the benefits of screening. It became apparent very early that he was not hearing impaired.
- Unnecessary.

Survey Feedback

A small number of respondents ($n = 17$) provided feedback on the survey. Their suggestions for improving the survey primarily included sending the survey soon after the birth of their baby as they had difficulty recalling the experience with newborn hearing screening. Other comments included concerns over the cost of the survey (i.e., use of tax payer's money), shortening the survey, and including a question regarding the birthing center/hospital where they delivered. The responses are provided below.

Feedback on Survey

- Also- I'd do better if this survey had arrived sooner.
- Suggest that these surveys are mailed closer to the baby's birth for I do not remember anything regarding my baby's hearing exam.
- My baby is 9 months old an earlier survey would be helpful for screening purposes. Thank you.
- No, but for surveys it would be easier to remember questions because this was too long ago to remember without being asked earlier.
- Not the process, but the survey. More accurate results/parent recall of events if the survey is sent out right after birth. Difficult to remember about the hearing screening or anything else in the 1st days after a baby is born
- Send survey out within 3-6 months of birth.
- Send the survey sooner--my baby is 9 months old now and it is hard to remember if we received certain pamphlets, etc. 9 months ago, or to remember who told us results, etc.
- Send the survey sooner-6 month is a long time to remember.
- Send these surveys out closer to birth date
- Send this survey sooner-closer to baby's birth- don't recall all info.
- Try getting this survey out to the parents a little sooner after the baby so the memory of the event is a little better.
- This questionnaire should come sooner than 6 months after. Had a hard time remembering. I think I don't remember much because we had no problems with hearing loss.
- I think this survey is a waste of tax payer's money.

- My question is why was this sent to me 6 months after my son was born? Will these results be used to get more grant money (with my taxes) for more surveys? I'm sorry, but this upsets me.
- Nothing. The survey was written very well. Thank you for caring.
- Also shorten survey would be nice...who will really respond to this intimidating packet.
- It might be worth having a separate survey question about where a person had hearing screening if it wasn't in their county's hospital.
- Should ask where the child was born and where child was tested (specific hospital)

Conclusions and Recommendations

The evaluation consultant and MNHP staff developed the following conclusions and recommendations based on the survey results.

1) Increased education

- The survey results clearly identified a need to increase education and involvement of parents in the newborn hearing screening process.
- Parents who had a homebirth noted a need for education directed at mid-wives and homebirth attendants. This education may help increase the likelihood that babies born at home will have their hearing tested, if not at the time of birth, at a separate appointment with their provider.

2) Continue quality improvement with hospitals

- Based on the feedback from parents, the MNHP will continue to work with hospitals on improving the quality of services including facilities and equipment used for newborn hearing screening.

3) Improve survey

- In an effort to improve and revise survey questions, future iterations of this survey will be pilot tested with parents. Specifically, parents will be given more opportunity to provide comments related to experiences with and attitudes about newborn hearing screening.
- A separate survey for each grouping of test results (i.e., passed, referred, hearing loss) will be developed.

ID# _____

Code: ☐PA ☐RSP ☐HL

Maine Newborn Hearing Screening Program Parent Survey

Congratulations on the birth of your baby! We would like to know what you think about the **Maine Newborn Hearing Screening Program**. Please answer the questions that you can. There are no right or wrong answers, please just be as honest as possible. Your answers are anonymous and confidential. Thank you for your help!

About You and Your Baby

- a. Date your baby was born _____
- b. Your relationship to baby: _____
(For example: mother, father, grandmother, grandfather, foster parent, etc)
- c. To what group does your baby belong (optional)
- | | | |
|---|-----------------------------------|--|
| <input type="checkbox"/> Caucasian | <input type="checkbox"/> Hispanic | <input type="checkbox"/> Native American |
| <input type="checkbox"/> African American | <input type="checkbox"/> Asian | |
- Other: _____
- d. What is your highest level of education?
- | | |
|---|--|
| <input type="checkbox"/> Some high school | <input type="checkbox"/> Some college or vocational school |
| <input type="checkbox"/> High school graduate/GED | <input type="checkbox"/> College degree |
| | <input type="checkbox"/> Graduate degree |
- e. County where you live? _____

About Your Baby's Hearing Screening

- 1) When did you first learn that your baby's hearing would be screened or needed to be screened?
- | |
|--|
| <input type="checkbox"/> Before hospital admission |
| <input type="checkbox"/> While in the hospital |
| <input type="checkbox"/> After hospital discharge |
| <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Other: _____ |
- 2) If you learned about the screen after discharge, who informed you?
- | |
|---|
| <input type="checkbox"/> Health Care Provider |
| <input type="checkbox"/> Audiologist |
| <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Not sure |
| <input type="checkbox"/> Not applicable |
- 3) We are interested in why some babies are not screened at birth. Parents have a right to refuse screening based on religious preference or other considerations.

Did you or your family refuse to have your baby's hearing screened?

☐ No

☐ Yes. Please explain why: _____

 **GO**

TO #21

Please turn to the next page

4) How were you **first** told about the **results** of your baby's hearing screening?

☐ The **staff or provider** at the hospital where my baby was screened told me **before** I went home.

☐ I received a card or note **before** I went home from the hospital.

☐ The **staff or provider** at the hospital where my baby was screened told me **after** I went home.

☐ I got a letter with the results mailed to my home.

☐ I was never told the results.  **GO TO #7**

5) What were the results of your baby's hearing test?

☐ Passed

☐ Referred for more testing

☐ I don't know

6) Please mark the sentence below that best describes how you understood the results of the hearing screening you baby had.

☐ My baby did not have a hearing loss

☐ It was *possible, but rather unlikely*, that my baby had a hearing loss.

☐ It was *possible* that my baby had a hearing loss.

☐ It was *very likely* that my baby had a hearing loss.

☐ It was certain that my baby had a hearing loss.

☐ I did not understand the results.

7) Thinking back on your baby's screening, please circle the number that indicates how much you agree with each statement

	Definitely Not disagree sure				Definitely agree
The people doing the screening NS were experienced with the equipment.	1	2	3	4	5
The people doing the screening seemed to have lots of experience NS working with infants.	1	2	3	4	5

The people doing the screening NS answered my questions.	1	2	3	4	5
Following the screening, I knew NS what I was supposed to do next	1	2	3	4	5

- 8) Overall, how satisfied were you with the **people** who provided hearing screening services to your baby?

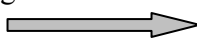
☐ Very satisfied
☐ Satisfied
☐ Somewhat satisfied
☐ Not very satisfied
☐ Not at all satisfied

Please turn to the next page

- 9) Overall, how satisfied were you with the hearing screening **services** provided to your baby and family?

☐ Very satisfied
☐ Satisfied
☐ Somewhat satisfied
☐ Not very satisfied
☐ Not at all satisfied

- 10) After your baby's hearing screening, what happened next?

☐ We returned to the hospital for another screen
☐ We were referred to the hospital audiology department for re-testing
☐ We were referred to an audiologist outside of the hospital for re-testing
☐ My baby's health care provider re-tested my baby's hearing in his or her office
☐ My baby was not re-tested after the first hearing screening  **GO TO #20**

- 11) How were you **first** told about the **results** of your baby's **re-testing**? (Please check one)

☐ The **staff or provider** at the hospital or office where my baby's hearing was re-tested told me **before** I went home.
☐ The **staff or provider** at the hospital or office where my baby's hearing was re-tested told me **after** I went home.
☐ I got a letter with the results mailed to my home.
☐ Other: _____

12) Please mark the sentence below that best describes how you understood the results of the **hearing re-testing** your baby had.

- ☐ My baby did not have a hearing loss
- ☐ It was *possible, but rather unlikely*, that my baby had a hearing loss.
- ☐ It was *possible* that my baby had a hearing loss.
- ☐ It was *very likely* that my baby had a hearing loss.
- ☐ It was certain that my baby had a hearing loss.
- ☐ I did not understand the results.

13) Overall, how satisfied were you with the **people** who provided **re-testing services** to your baby?

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Somewhat satisfied
- ☐ Not very satisfied
- ☐ Not at all satisfied



14) Overall, how satisfied were you with the **re-testing services** provided to your baby and family?

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Somewhat satisfied
- ☐ Not very satisfied
- ☐ Not at all satisfied

Please turn to the next page

About Your Baby's Hearing Loss Diagnosis

15) **After your baby was diagnosed with a hearing loss**, how many times has he or she been to an appointment with an audiologist?

- ☐ 0  **GO TO # 17**
- ☐ 1
- ☐ 2-3
- ☐ 4-5
- ☐ 6 OR MORE
- ☐ Not applicable, my baby was not diagnosed with hearing loss  **GO TO #20**

16) How satisfied are you with the care and services your baby's audiologist is providing?

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Somewhat satisfied
- ☐ Not very satisfied

☐ Not at all satisfied



17) If your baby has **not** been to an audiologist since you learned that he or she had a hearing loss, what are the reasons (Please check all that apply)

- ☐ We have an appointment scheduled
- ☐ I have not been able to find an audiologist who works with infants and young children
- ☐ I have not found an audiologist who accepts my baby's health plan.
- ☐ I have not found an audiologist who is close enough to where we live.
- ☐ My baby's health care provider told me my baby does *not* need to see an audiologist
- ☐ I don't think my baby needs to see an audiologist
- ☐ Other: _____

18) Are you and/or your baby receiving support from early intervention providers?

☐ No

☐ Yes **GO TO #19**

18a) What are the reason(s) your baby is **not** receiving support from early intervention providers?

(Please check all that apply)

- ☐ Insurance does not cover early intervention services
- ☐ I was told my baby was not eligible for early intervention services
- ☐ By whom? _____
- ☐ I chose not to have my baby participate in early intervention services.
- ☐ The health care provider told me that my baby did not **need** early intervention services.
- ☐ The audiologist told that my baby did not **need** early intervention services.
- ☐ No one contacted me after my baby was referred to early intervention.
- ☐ I have not been contacted about early intervention services.
- ☐ Other: _____

Please turn to the next page

19) Please list **up to 4 services** your baby has received or is receiving to help with his or her hearing loss

Agency Providing Service	Type of Service	Age of baby when service began	Quality of Service				
			Excellent				Poor
			1	2	3	4	5
			Excellent				Poor

			1	2	3	4	5
			Excellent				Poor
			1	2	3	4	5
			Excellent				Poor
			1	2	3	4	5

20. The Maine Department of Health and Human Services, Newborn Hearing Screening Program provides information to parents about hearing screening and hearing loss in babies and young children. In order to improve our program, we'd like to know if you received our information.

Did you receive the following information about hearing screening or loss in babies and young children?			
	Yes	No	I don't know
From the hospital: <i>Hearing in Infants & Young Children, A Guide for Parents</i>			
From the audiologist: <i>Resource Guide for Families of Children with Hearing Loss</i>			
From ECFS/Early Childhood and Family Services: <i>Family Information Notebook</i>			

21) Do you agree or disagree with the following statements about newborn hearing screening?

Agree Disagree

___ ___ Screening allows parents to do something positive if their baby has a hearing loss.

___ ___ Screening leads to early diagnosis if the baby has a hearing loss.

___ ___ Screening leads to early treatment if it is needed.

___ ___ Screening makes parents worry unnecessarily.

___ ___ Screening takes too much effort

___ ___ Screening wakes or upsets the baby.

22) If you had another baby, would you want him or her to have his or her hearing screened? Please turn to the next page

___ Yes

___ No

___ Not sure

23) How are your baby's medical expenses paid?

- ☐ MaineCare
- ☐ Private insurance
- ☐ Self-pay

24) Please list any suggestions you have for improving the newborn hearing screening process:

Thank you for your help with this survey! Your responses will help us improve the hearing screening process for all families.

**If you have any questions or if you'd like further information please call the
Maine Newborn Hearing Screening Program**

Phone: 207-287-6879

Toll-free: 1-800-698-3624

TTY: 1-800-606-0215